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Experiences of Living with Visible Difference: Individual and Social Reflections

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Abstract

Many health conditions impact upon an individual's appearance and result in an altered appearance ("visible difference"). The presence of visible difference is associated with a variety of psychosocial difficulties and challenges, yet calls for an integrated theory of adjustment remain largely unanswered. This qualitative research, conducted in the United Kingdom, drew upon 22 interviews conducted with participants who had a variety of visible differences. It examined their experiences and reflections related to their difference and the impact that their visible difference had upon their lives. A thematic analysis produced two themes. The first of which was predominantly concerned with the impact of visible difference upon the individual whilst the second captured the inherently social nature of appearance and appearance based judgements. The analysis is considered in light of the contention that an integrated theory of adjustment to visible difference is required and participants' experiences with healthcare professionals and the implications for those providing care are introduced.

Introduction

A wide variety of health conditions may impact the appearance of the individual. An altered appearance or disfigurement (a 'visible difference') may result from congenital or genetic conditions, disease processes, and the consequences of treatment or acute traumatic events (Kent & Thompson, 2002). Visible difference is of itself relevant to health and well-being and thus of legitimate concern to the healthcare profession. Its presence is associated with a broad range of psychosocial challenges in a significant minority of those with a difference (Harcourt & Rumsey, 2008). These include raised anxiety levels, depression, social anxiety, social avoidance, and reduced quality of life (Rumsey, Clarke, & White, 2003). Visible difference may evoke negative reactions from others (Thompson & Kent, 2001), stigmatisation (Goffman, 2000), and contribute to lowered self-perceptions and difficult social interactions via a spiral of negative emotions, maladaptive thought processes, unfavourable self-perceptions, and unfavourable behavioural patterns (Rumsey & Harcourt, 2004).

These psychosocial difficulties are, however, not well predicted by the specific type or nature of the difference or its size (Rumsey et al., 2003; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). Neither is there a linear relationship between objective measures of severity and distress, with an individual's subjective evaluation of their difference being more strongly related to psychological adjustment (Moss, 2005; Ong et al., 2007).

Despite the recognition that visible difference may be accompanied by psychological distress and challenging social interactions, a complete understanding of the mechanisms through which these occur remains elusive. Kent (2000) has argued for an integrated theory, evidencing the utility and applicability of four psychological models of visible difference (a social anxiety model, the sociological models of stigma, social skills training and the body image schema model) to the experiences of those with vitiligo. Such integration has not yet fully occurred.

Furthermore, there exists a rather limited body of qualitative research focussed on exploring adult's experiences of visible difference as opposed to that focussed upon a specific condition. For

example, like Kent (2000), Thompson, Clarke, Newell, Gawkrödger, and ARC (2010) drew on the experiences of those with vitiligo. Other studies have concentrated on the experiences of those with specific conditions such as epidermolysis bullosa (Dures, Morris, Gleeson, & Rumsey, 2011) and cleft lip and/or palate (Stock, Feragen, & Rumsey, 2015). Qualitative research which has focussed upon visible difference has not examined the comments of Kent (2000) and has had a specific focus such as positive adjustment (Egan, Harcourt, & Rumsey, 2011), managing intrusive reactions (Thompson & Broom, 2009), or the romantic experiences of adolescents (Griffiths, Williamson, & Rumsey, 2012) rather than examining lived experiences of visible difference more broadly.

The current research therefore aimed to explore the appearance related experiences and reflections of participants with a variety of visible differences and examine any perceived impact of their difference upon their life. It was also intended that the findings be used in order to consider the contention of Kent (2000) that an integrated theory of adjustment to visible difference is required.

Materials and Methods

Method

Participants' personal experiences were explored through the medium of semi-structured individual interviews. The present data form part of a larger data set collected during interviews exploring visible differences and intimate, romantic relationships, reported in (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2018) and which were intended to be used in the development of a research measurement tool or scale focussed upon this topic.

The research received ethical approval from the University of the West of England faculty research ethics committee. The interviews were largely composed of two distinct sections with the first part of the interview considering participants' feelings and experiences of visible difference generally and the second part focussing on romantic relationships. The section of the interview guide that related to participants' more general feelings and experiences are included in Table 1. As

the interviews were semi-structured in nature, the questions were deployed flexibly and responsively.

Table 1. *Semi-Structured Interview Guide Questions*

Questions
Could you tell me a little about the nature of your visible difference?
How important do you think appearance is in general, does it matter what we look like?
How do you feel about your own appearance?
Speaking generally, would you be able to describe any impact that your appearance has had upon your day to day life?
Could you tell me about any changes over time in how you feel about your appearance and any impact it has on your life?

Participants were offered a choice of whether to participate via the phone, in person, or by means of an internet mediated video service. This choice ensured consistency across the data set as all data were produced via contemporaneous, immediate verbal exchanges. This choice was offered in recognition of the arguments that phone interviews can produce high quality data, can be appropriate for sensitive topics, and as concerns about their utility have little evidential basis (Novick, 2008). Interviews were performed by the first author, digitally recorded, and transcribed verbatim.

Participants

The study was advertised by 17 relevant support groups and charities, through the social media of the research centre in which the first author is based, and via a University press release. Twenty-two participants were interviewed. This included 16 women and six men. Participants were aged between 25 and 64 with an average age of 43 years. Six were single and the other 16 were in a relationship or married. Interviews lasted an average of 65 minutes. Of the 22 participants, 15 chose to be interviewed over the phone, five in person and two via skype. To protect participant anonymity, pseudonyms have been used in this report.

Eight participants had a condition that had been present since birth, the remaining 14 had acquired their visible difference at a subsequent stage of life. Twelve participants indicated that their difference was ordinarily visible to other people, the other 10 participants did not believe this to be so. Eight participants had a condition they described as congenital or genetic, whilst the remaining 14 had acquired their difference through injury, illness, or disease. The participants' visible differences were: Alopecia (five participants), Ankylosing Spondylitis (one), Breast Cancer-related Scarring (two), Cleft Lip and/or Palate ('cleft') (six), Facial Birthmark (one), Facial Palsy (one), Facial Palsy and Breast Cancer-related Scarring (one), Facial Scarring (one), Ichthyosis (one), and Psoriasis (three).

Analysis

The data were analysed via inductive thematic analysis following the six steps detailed by Braun and Clarke (2006, 2013) and as described in Sharratt et al. (2018). An inductive form of thematic analysis was employed as the data were focussed upon individual experiences and so an explicitly and primarily data-driven approach was considered appropriate, although the authors' personal experiences and knowledge of existing literature are acknowledged as being relevant to the performance of the research, including the analysis.

The eventual goal of the research programme, to devise a research tool, and the intention of utilising the data in order to interrogate the call of Kent (2000) for an integrated theory of visible difference, meant that the broader implications of the data would be considered. The Pragmatism of Morgan (2007, 2014) was therefore an appropriate paradigm from which to conduct this research in recognition that the transferability of the findings would be considered, the abductive nature of the analysis, and the intersubjectivity inherent in examining participants' unique interpretations of, and reflections upon, their experiences. The theoretical flexibility afforded by thematic analysis (Braun & Clarke, 2006) meant that it was appropriate for this research.

In a process which further reflected the intersubjectivity (Morgan, 2007) that characterised this research, the analysis was conducted by the lead author and verified through discussion and

consultation with the co-authors until consensus was reached, described in Sharratt et al. (2018).

Results

The analysis resulted in the generation of five main themes each with several sub-themes. Three of the five themes were specific to intimacy and romantic relationships and are reported by Sharratt et al. (2018). The two remaining themes were concerned with the broader impact of visible difference upon participants and are reported here. The first, 'Personal Reflections on Looking Different' was concerned with the individual impact of visible difference upon participants. In contrast 'Our Socially Situated Appearance' focussed upon the belief that appearance is an intensely social phenomena, shaping interactions with others. These two themes, their associated sub-themes, and example codes are illustrated in Table 2.

Table 2. *Themes, Subthemes, and Example Codes*

Theme	Subtheme	Example codes
Personal Reflections on Looking Different	Becoming one with difference	Reduced confidence
		Positive growth
	Hiding away	Cover difference
		Avoidance
Our Socially Situated Appearance	This lonely planet	Others not understand
		Lack support
	Appearance as a projection	First impressions
		Judgement
Being public property	Intrusion	
	Assumptions	
	Searching for comparative normality	Downward comparisons Upward comparisons

Personal Reflections on Looking Different

This theme detailed participants’ understanding of the primarily negative individual and personal consequences of living with a visible difference. These included the perceived impact upon participants’ personal characteristics, the behaviours that they adopted in connection with their appearance, and the availability of appropriate support. The focus was very much upon the impact of appearance at the level of the individual. This theme contained three sub-themes. First,

'Becoming One with Difference' conveys participants' understanding that their personal identity and characteristics have been influenced by the presence of a visible difference. Some of the sentiments expressed in this sub-theme were offered as explanations for various avoidant behaviours that were contained within the second sub-theme, 'Hiding Away.' The final sub-theme 'This Lonely Planet' describes the sense of isolation that participants experienced and the tendency of family, friends and professionals to underestimate the impact of visible difference. The experience of effective support was the exception rather than the norm.

Becoming one with difference. Participants explained that they believed their difference to have affected their personal traits and attributes in a number of ways. In the main, these impacts were experienced as detrimental and included reductions in confidence and increased self-consciousness:

I am quite self-conscious and I am quite sensitive. I can take offence quite easily. I do look for trouble. It's definitely affected me. (Pauline, Ichthyosis)

Several participants discussed how their difference had compromised their identity or sense of self. This appeared particularly pertinent where the difference was acquired and, prior to this acquisition, appearance had formed a significant part of their identity:

My confidence has taken a massive blow, particularly... I was known for "Oh [Ruth]'s got long blonde hair" and then suddenly I had nothing... without it you do sort of feel lost. (Ruth, Alopecia)

A number of participants considered that these effects diminished as they aged and learned to accept their appearance. Furthermore, a minority argued that the adversity they had to contend with in connection with their difference fostered positive growth, determination and resilience:

If I wasn't born with a cleft lip and palate I wouldn't have the confidence or the determination that I have now. (Luke, Cleft)

Hiding away. This sub-theme portrayed behaviours that participants adopted in order to reduce or minimise the visibility of their difference and present themselves as 'normal'. This was achieved through the strategic use of clothing, make-up, hair and hairpieces, facial expressions, and body language designed to exert control over the external visibility of their difference. This could involve considerable financial expense, time, inconvenience, or discomfort:

I'll still get up and put make-up on before we go outside and climb and I even think to myself "this is ridiculous" and a waste of time and money but I still do. (Chloe, Facial Birthmark)

Participants understood that they were motivated by the desire to avoid others seeing their difference, despite some suggestion that the reality was not as hurtful or damaging as initially feared:

I forced myself... "right, I'm going to do this, I'm going to go to the shops on my own and I've got to do it." Although I was sweating and I was a bit nervous... and sort of like no-one looked at me, barely took any notice, so I felt better for that. (Valerie, Facial Palsy and Breast Cancer)

Beyond this concealment of difference, participants also communicated avoidant behaviour and their withdrawal from social situations, interactions, events, locations, situations, and activities. Commonly it was contexts that involve the expectation of scrutiny from others or the exposure of the body that were most problematic:

Walking to into a pub is my wors... along with high school, is the worst thing, not that I go to pubs and that's probably why I don't. (Charlotte, Cleft)

At its extreme this avoidant behaviour was debilitating and could exert a profound impact upon an individual's quality of life:

I'd say walk a mile in my shoes when I feel that I can't leave the house, which is kind of difficult to do really isn't it? (Eleanor, Psoriasis)

This lonely planet. The final sub-theme represented participants' belief that it is extremely difficult for those that do not have a visible difference to fully understand the powerful impact it exerts upon their lives and therefore to offer empathetic support. Participants felt that those they were closest to had become accustomed to their difference to the extent that ongoing recognition of the challenges of difference from significant others in their lives was difficult to obtain:

I suppose maybe they think that I'm over it or it doesn't affect me or what does it matter... But you know, sometimes I just think sometimes people are a bit insensitive but... it'd be like talking about "oh my best friend's pregnant" or something when the other one's just had a miscarriage. (Elaine, Alopecia)

This extended into the provision of support by the healthcare profession, which was felt to be inadequate. Participants believed that the healthcare profession did not address the social and psychological consequences of visible difference, with the focus of care limited to the biomedical sphere:

I went for laser removal when I was 17 and then, at the same time, they sent me to a camouflage make-up specialist but it was always about removing it or hiding it. There was none, there was nothing about... support for living with it or accepting that it's there and not hiding it and not removing it... it was all very much like "It's not normal we'll get rid of it" rather than "It's fine" and ways of living with it. (Chloe, Facial Birthmark)

Likewise, a minority of participants detailed experiences of healthcare professionals overlooking or even explicitly dismissing their appearance concerns, with one participant feeling compelled to conceal her true motivation for having a prophylactic mastectomy of her healthy breast following Breast Cancer due to fear that her appearance concerns would be considered vain, superficial or '*shallow*':

I had to go and see a counsellor, talk to someone about why I wanted it, I couldn't really, I didn't feel comfortable talking to them about the aesthetics. I only really wanted this because I wanted to look normal. I had to speak more on the health side of it... but I just felt at the time that I couldn't really discuss it with anybody. (Jodie, Breast Cancer)

Participants felt it was important that psychological and social support was available to those with a visible difference. Possibly because of the perceived barriers in communicating with healthcare professionals and their experiences of a lack of empathetic support, participants voiced a preference for peer-to-peer and expert patient led support.

I think a peer group is probably definitely the strongest way to move on (Luke, Cleft)

A small minority of participants, however, recounted negative experiences of support groups, indicating that they could be emotionally traumatic as they may raise concerns about the future progress of a condition, involve judgment and comparisons being made by and about those present, and be particularly distressing:

(I) remember going to one support group meeting, which actually did really put me off because I turned up... and they'd all got their wigs on and it was just like "oh my God!" and I did come to realise I was further down the line than I thought I was and actually I had come to accept it because every time anyone spoke, they started crying. It was really just awful (Anna, Alopecia)

Our Socially Situated Appearance

This theme emphasised the inherently social nature of appearance. Concerns about the negative reactions and judgements of others were understood to underpin some of the individual difficulties previously introduced. The 'Appearance as a Projection' sub-theme explains these concerns by positing that appearance is considered a projection of the self into the World and that a person's 'looks' say something fundamental about the individual concerned. One consequence of having an observable difference was to deny participants their privacy, discussed in 'Being Public Property.' The final sub-theme, 'Searching for Comparative Normality' describes the tendency of participants to make their own appearance based comparisons.

Appearance as a projection. All participants considered that appearance was perceived by others to comprise a projection of the self and was subject to constant scrutiny. This was considered

especially pertinent as initial impressions were formed and, crucially, was represented by participants as a process laden with value judgements:

You kind of assume someone who's fat is lazy, which is not always the case really. (Beth, Facial Scarring)

The tendency to look at others' differences and appraise someone on the basis of their appearance was explicitly considered to be normal or natural by some participants and so pervasive, ingrained and automatic that they themselves would also sometimes judge others in this way.

Speaking about someone with a physical disability Michelle said:

When I very first met him I did presume that mentally, intellectually that he's not, sounds bloody awful doesn't it, not on the same sort of wavelength..... which now, saying it, sounds absolutely awful... I shouldn't just presume that for any reason his intellect or mental state is affected by it at all. (Michelle, Alopecia)

Participants considered this phenomena to be reinforced by media images and messages that dictate what constitutes a desirable appearance and exert pressure on individuals to conform to appearance ideals. This issue was considered especially pertinent and of more consequence for women than for men:

I feel sorrier for girls than blokes. Feel sorry for them all but the same thing about the way you look, I think it's more savage for a girl. (David, Cleft)

Although prone to making some evaluations about others based upon difference themselves, in the main participants often considered that they and their close friends and family as

subsisting outside of an otherwise appearance obsessed world. Having a difference and having contact with someone else with a difference was thus believed to engender a more open, accepting attitude in participants and those around them:

My children being acceptable of people's differences. It's no big deal, they don't kind of do the whole pointing and staring. (Charlotte, Cleft)

Being public property. Participants recounted experiences of intrusive stares, prolonged glances and uninvited comments and questions. This went beyond the private judgements that were believed to be made in the previous sub-theme, extending into behaviour:

If I do wear short sleeved stuff, short sleeved attire that's when a) I feel most ill at ease and b) when I'm more likely to catch criticism or, erm, horror or aversion from other people. (Austin, Psoriasis)

In cases in which a particular appearance is commonly associated with a specific health condition, such as women's hair loss and cancer, participants felt that others automatically assumed that they were ill. This belief appeared to offer permission to others to ignore normal social boundaries, overriding participants' right to privacy. This led Florence to feel compelled to engage in an uninvited conversation even though:

You don't want to talk to some stranger in the street, when other people are around, about what is or isn't wrong with you. You know, it's not, none of their business really. (Florence, Alopecia)

Whilst a small minority of participants said they did not mind being asked about their appearance, most who discussed this considered this an unwelcome invasion of their privacy and found it distressing. As privacy was implied by participants to be a basic right or politeness that individuals should extend to one another, the denial of it based on a socially stigmatised characteristic may be interpreted as discriminatory and a dehumanising experience.

Searching for comparative normality. Whilst participants made a small number of upward comparisons in which they compared themselves to those they considered more fortunate, most appearance based comparisons were downward. Participants presented themselves as relatively lucky or unaffected:

My nose looked different... I mean it's still hooked now, it's not right but it could be a lot worse, put it that way. So that's another thing you think of as well. As a person I think "well it could be a lot worse." (Pete, Cleft)

These comparisons centred on the apparent severity of a difference and how far it distinguished someone from the norm. As such, they acted to normalise participants and potentially neutralise any threat or harm or their identity and self-esteem that was attached to their difference. They also acted to reproduce and reinforce the appearance norms and expectations of conformity that participants experienced as problematic.

Discussion

These findings emphasise that participants with a visible difference considered appearance to be of central importance to their experiences of contemporary UK life. Their experiences of difference had exerted a substantial individual and social impact. Generally these impacts were considered negative, though there was some evidence of belief in positive adjustment and growth

(Egan et al., 2011). The findings strongly allude to at least three of the four theories highlighted by Kent (2000). Dealing with each, the contention of Leary and Kowalsk (1995) that social anxiety reflects a universal concern about exclusion and rejection is evidenced throughout as participants' physical projection into the world was understood to be met with adverse judgements (Appearance as a Projection). It is conceivable that this contributed to reduced confidence (Becoming One with Difference) and impression management via safety behaviours such as concealment and avoidance (Hiding Away) in an attempt to minimise the likelihood of exclusion and rejection.

Experiences of stigma (Goffman, 2000) were relevant within the sub-theme 'Being Public Property.' This included instances of both enacted and felt stigma (Scambler & Hopkins, 1986). Enacted stigma was experienced when a difference was visible to, and therefore known by, others who responded negatively to visible difference. Moreover, participants acknowledged that they may sometimes experience feelings of stigmatisation (felt stigma), even in the absence of enacted stigma (Hiding Away). The 'Hiding Away' sub-theme also constitutes evidence of an attempt at 'passing' (Goffman, 2000) as those whose stigmatised identity is concealable may attempt to pass themselves as non-stigmatised individuals.

Participants' beliefs that cultural influences such as the media provide messages that dictate and reinforce those aspects of appearance that are considered desirable and that such concerns are especially relevant for women (Appearance as a Projection), neatly encapsulate the body image disturbance model of Cash and Grant (1996). The particular concern over contexts involving bodily exposure and social scrutiny (Hiding Away) complete the alignment with Kent's (2000) description of this model.

Finally, the social skills model of Rumsey, Bull, and Gahagan (1986) and Partridge (1998) (both cited by Kent, 2000) may garner some, limited, support from this work. The potential for avoidant behaviour (Hiding Away) together with the obvious difficulty that intrusive reactions caused (Being Public Property) and the sense of isolation that was recounted (This Lonely Planet),

suggest that some social interactions were experienced as challenging and that social skills training may therefore prove beneficial.

In addition to the four models Kent (2000) discusses, the results provide support for the socio-cognitive fear avoidance model (Newell, 2000; 1999). The avoidance and concealment detailed in the 'Hiding Away' sub-theme provided an indication that avoidant behaviours are adopted but, ultimately, can lead to a restriction in activities and exposure as the feared context is circumnavigated. Consequently, strategies and techniques that may alleviate it are never acquired, and a level of isolation may be experienced (This Lonely Planet). Similarly, the routine avoidance of certain activities may contribute to the reduced self-confidence and increased self-consciousness discussed within 'Becoming One with Difference.'

The applicability of, and overlap between, each of these models combined with the nature of the accounts provided suggests that the call of Kent (2000) for an integrated or unifying theory of adjustment to visible difference should be heeded. Whilst the Appearance Research Collaboration has offered a working framework of adjustment to disfiguring conditions (reported in Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014) this is acknowledged by the authors as being a somewhat subjective, provisional, working model, in need of further development and refinement. The current research suggests that such development and refinement should account for the models discussed by Kent (2000) and offered by Newell (2000; 1999). This may be considered a research priority as the lack of a unifying theory remains a substantial and substantive challenge to researchers concerned with the psychosocial aspects of visible difference and may impede the provision of holistic healthcare.

Clinical Implications

The accounts of participants and, particularly, the sub-theme 'This Lonely Planet' suggest that visible difference can entail considerable psychosocial difficulties. In addition, professional support may be inadequate, unavailable, or may fail to fully acknowledge these concerns. Some of

the episodes that participants recounted in relation to this topic had occurred several years before and so it is possible that patients' experiences may be different today, although ensuring healthcare professionals are aware of the potential impact of visible difference and are able to respond sensitively should be considered a priority. This is especially pertinent as dedicated psychological support for visible difference may not always be readily available.

Access to this support may fluctuate as a factor of the condition with which the patient presents. For example, psychological support is embedded within the multidisciplinary care that NHS Cleft Lip and Palate services provide to children and young people and may feature within services providing care for Burns and Cancer, but may not be routinely offered to those with other conditions, such as dermatology patients. Furthermore, the extent to which appearance concerns are addressed within these services may vary. Whilst a dedicated service named 'Outlook' has been established in Bristol to provide psychological support to those with visible difference, it remains unique within the UK and elsewhere.

Offering psychological support to all persons with a visible difference may be resource intensive but this study suggests that the healthcare experience may be improved where healthcare professionals are aware of their patients' appearance concerns and are willing to acknowledge these as key influences on their well-being. Participants' desire for peer and expert-patient support coupled with the small number of distressing experiences reported in connection with peer support groups indicates that formal healthcare structures and professionals could perform a role in facilitating, guiding, and supporting this interaction in an economical, cost effective manner.

Limitations

This research provided participants a choice of how to engage with the research. The accounts offer rich insights into the experience of those with visible difference and how these experiences may relate to theory and to the provision of healthcare. The research was, however, conducted primarily with persons recruited through support groups and charities that operate

within this field. The experiences and beliefs of the participants concerning their visible difference and the subsequent analysis of their accounts, may therefore not reflect or include those who are less engaged with such organisations.

The participants were predominantly women and so whilst the experiences of men were captured, women's experiences are more strongly represented. All interviews were conducted by the first author, a male researcher who does not consider himself to have a visible difference. It is possible that these personal characteristics may have influenced the willingness of potential participants to engage with the research, the nature of the accounts provided, and the approach to the analysis of the data.

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